

# Communicating uncertainty can lead to less decision satisfaction: a necessary cost of involving patients in shared decision making?

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## Abstract

**Background** Given the large number of interventions of uncertain effectiveness, research on communicating uncertainty is needed to examine its impact on patients' health decisions.

**Objective** To examine physicians' communication of uncertainty and its impact on patients' decisions and decision satisfaction.

**Design, setting, and participants** Participants included female patients seen in a breast health centre whose physicians were discussing a decision with them, with no clear 'best' choice based on outcome evidence.

**Main variables** Decision communication was measured using the OPTION scale, a measure of the degree to which physicians involve patients in a decision-making process. One-to-two weeks after the discussion, patients reported their satisfaction with the decision-making process and their decision. Decisions were verified in medical charts with patient consent.

**Results** Seventy-five women agreed to participate (94% response rate). The mean translated score of the OPTION scale was 68.0 (SD 18.3), but only 33.2 (SD 19.1) for the uncertainty items. Among cancer patients, communicating uncertainty was negatively related to decision satisfaction ( $P < 0.002$ ), and there was an interaction between patient involvement in decisions and communicating uncertainty in relation to patients' decision satisfaction ( $P < 0.03$ ).

**Discussion** Communicating scientific uncertainty might lead to less decision satisfaction among women facing cancer treatment decisions; this could be a natural outcome of the decision making process. Involving patients in decisions might help them tolerate uncertainty.

**Conclusion** Future studies should consider assessing other outcomes (e.g. knowledge, physician support) of the decision making process. There may be trade-offs between acknowledging uncertainty and immediate decision satisfaction.

There has been a growing body of research on communicating risks and benefits of treatment options to patients (e.g.<sup>1–3</sup>) for informed or shared decision making. The goal of shared decision-making is to improve patients' decision-making process, and to match patients' intervention choices with their preferences for the benefits and harms of intervention options.<sup>4</sup> Experts assert that shared decision making is essential when there are no clear standards of care or guidelines for patients' treatment decisions, and when patients' preferences for risks and benefits of interventions influence choices.<sup>4,5</sup>

Most medical decisions are complicated by uncertain or unknown evidence about risk/benefit information.<sup>6</sup> However, little is known about how to communicate this scientific uncertainty (the quality of risk information) to patients,<sup>7</sup> including uncertainty about statistical risk (e.g. wide confidence intervals), and uncertainty about the strength and quality of available evidence used to make health decisions.

Physicians are often hesitant to communicate uncertainty to patients,<sup>8</sup> despite the prevalence of uncertainty in medical decisions. Some physicians have been trained to accept and manage uncertainty internally, and provide a confident recommendation to patients as they guide them in clinical decisions.<sup>9</sup> Physicians may also believe that communicating the complexity of uncertainty will overwhelm and confuse patients.<sup>10</sup> Full disclosure of scientific uncertainty in addition to discussion of options could actually impair patients' ability to make informed decisions, particularly for those with lower numeracy skills.<sup>11–13</sup> Some patients also avoid statistical uncertainty ('ambiguity aversion') and defer or reject decision-making as a result.<sup>12,14</sup> Thus it remains unclear whether communicating scientific uncertainty about risks and benefits aids patients' decision making.

Communicating scientific uncertainty could affect patients' decision satisfaction. For instance, some patients such as those who are older do not always want to participate in decisions involving estimates of probabilities.<sup>15,16</sup> Patients with lower numeracy skills

might also feel less comfortable with the amount of information required to understand scientific uncertainty and make informed decisions.<sup>11</sup> For these patients, discussing scientific uncertainty with their physician could lead to confusion and lower decision satisfaction. However, others report that acknowledging scientific uncertainty is more trustworthy and reflects the true nature of medical decisions;<sup>1</sup> patients with these beliefs could feel more satisfied and comfortable with their decisions after discussing scientific uncertainty with their physicians.

Given the increasing focus on shared decision making, and the large number of interventions of unknown or uncertain effectiveness, research on communicating scientific uncertainty is needed to examine the impact of uncertainty on patients' clinical decisions. The proposed study was developed to examine patient–physician communication of scientific uncertainty and its impact on decisions about surgery and decision satisfaction among women seen in a breast health centre. The study aims were to: (i) explore the relationship between communication about uncertainty and patients' surgical decisions and decision satisfaction and (ii) explore whether demographic variables, cancer disease status, or patients' numeracy moderate the relationship between physicians' communication and patients' decisions about surgery and decision satisfaction.

## Method

Women were recruited from a breast health centre in Providence, RI. Physicians identified women who would be facing a decision about surgery that involved uncertainty, where there were multiple options available and patient preferences might dictate intervention choices. These patients would be presented with two or more intervention options with no clear 'best' choice based on outcome evidence. For instance, women could be deciding on a lumpectomy or mastectomy for multiple small tumours in the same breast quadrant, or could be deciding on surgery vs. active screening for multiple areas of atypical hyperplasia.

Recruitment occurred between February and September 2008. A total of 80 women were eligible and approached about the study; 75 agreed to participate (94% response rate). Women were asked whether the researcher could observe their appointment, whether they would complete a survey after their appointment, and whether they would complete a follow-up survey about their decision making process 1–2 weeks later by telephone. Participants were paid \$10 at the time of their appointment for participating. With their consent, women's decisions were verified through their medical charts. Patients' choices were compared with either the multidisciplinary tumour board's recommendation (when applicable), or their physician's recommendation as documented in the medical chart. The institutional review boards of the academic institution and affiliated hospitals approved this study.

## Measures

### *Participant characteristics*

Participants were asked questions about their age, race, ethnicity, education, income and medical history.

### *Decision communication*

Decision communication was measured using the OPTION scale,<sup>17,18</sup> an observational measure of the degree to which physicians involve patients in decision-making. We added three items to the OPTION scale to measure communication of uncertainty: 'The clinician discusses stochastic uncertainty (the notion of chance),' 'The clinician discusses probabilistic uncertainty (uncertainty about risk estimates, e.g. CIs),' and 'The clinician discusses evidentiary uncertainty (uncertainty about strength or quality of the evidence in the literature).' These items were scored in the same manner as the original scale items (from 0 to 4), and the mean was translated into a score out of 100 as scored in the original OPTION items. Higher scores on these added items indicated a better communication of uncertainty in ways defined by

the international experts in risk communication (e.g.<sup>2,4,5</sup>) as there are no standards for communicating scientific uncertainty at this time.<sup>7</sup> For instance, for probabilistic uncertainty, higher scores were coded if physicians communicated a range of frequencies or percentages (e.g. 'approximately 20–25% of women just like you...'). Lower scores were coded if physicians used general qualitative descriptors such as 'a small number of women...' or 'in our best estimate, most women...' For evidentiary uncertainty, higher scores were coded if physicians referred to literature or clinical guidelines when discussing uncertainty, with more and clearer detail indicating higher scores.

### *Reactions to uncertainty*

The revised *Physicians' Reaction to Uncertainty Scale*<sup>19,20</sup> is a 15-item scale that measures attitudes towards uncertainty in medical practice in four areas: anxiety from uncertainty, concern about bad outcomes, reluctance to disclose uncertainty to patients and reluctance to disclose mistakes to physicians. Physicians completed this scale at the end of the study. We also adapted the *anxiety from uncertainty* subscale for patients to assess how patients respond to uncertainty in medicine, using parallel items (Cronbach's alpha = 0.80).

### *Numeracy*

Patients' ability to comprehend statistical information was measured using the Subjective Numeracy Scale,<sup>21,22</sup> an 8-item scale that asks patients to rate their numerical ability and preference for hearing statistical information. This scale has been correlated with actual numeric ability, and has the advantage that it does not require patients to perform mathematical calculations.

### *Decision satisfaction*

Patients were asked to rate their satisfaction with the decision making process approximately 1 week following their appointment on a 6-point scale from not at all satisfied (1) to extremely satisfied (6), per previous studies using single-item measures (e.g.<sup>23</sup>).

## Data analysis

Three dependent variables were used in the analysis. Patients' surgical choice was dichotomized in two ways: (i) consistent vs. inconsistent with the physician's or multidisciplinary teams' recommendations for treatment, as documented in the medical chart (e.g. if a patient's choice deviated from any of the multiple suggested options presented to her, the choice was coded as 'inconsistent'; for instance, one patient chose to have a partial mastectomy when presented a choice between a total mastectomy or neoadjuvant chemotherapy before surgery) and (ii) more vs. less aggressive choice as verified by the physician's or multidisciplinary team's recommendations in the medical chart (e.g. one patient chose not to have chemotherapy when presented with a choice; that choice was coded 'less aggressive' of the options presented). Patients' decision satisfaction was also dichotomized into highly satisfied vs. otherwise because most patients tended to report values on the higher end of the scale (e.g. 3–6). We asked patients to rate their decision satisfaction after making a decision, but before surgery so the surgical outcome would not bias their satisfaction. We expected that most would report high levels of satisfaction soon after a choice was made, and we were interested in examining those who were not fully satisfied at that time. The explanatory variables included the measure of quality of physicians' decision communication (modelled on a continuous scale using the OPTION scale total score from the original 12 items, and uncertainty score from the three added items). Patients' disease status (modelled as a binary variable, cancer diagnosis vs. no cancer diagnosis), ability subscale on the Subjective Numeracy Scale and demographic variables were explored as possible moderator effects of the relationship between decision communication and patients' decision satisfaction, and decision communication and patients' choice.

We fitted a generalized linear mixed effects model (GLMM) to the data. Since the dependent variables were binary, we explored logit, probit, log-log and complementary log-log link

functions for relating the probability of a highly satisfied response to the explanatory variables. We then replicated the analyses for the other dependent measures of consistent vs inconsistent choice, and a more vs. less aggressive choice compared with physicians' recommendations as documented in medical charts.

It is possible that participants assigned to the same physician had similar responses (e.g. patients of one physician might be more satisfied than those of another physician, or might choose similar treatments). This potential clustering in the data was modelled by introducing physician-specific random effects into the model. We fit models with random effects in the intercept and the parameters corresponding to the explanatory variables. Parameters in the GLMM were estimated using maximum likelihood algorithms and the generalized estimating equations (GEE;<sup>24,25</sup>), following appropriate adjustments on the correlation structure for binary data.<sup>26</sup> Tests of significance were performed using the asymptotic normal distributions of the parameter estimators. SAS version 9.0 and lme4 package of R software were used for analyses.

## Results

### Study participants

Table 1 describes the study participants. Participants were 51 years of age on average (range 26–82) and were seen by one of five breast surgeons (three males, two females). Most participants were White, Not Hispanic (76%) and more than half (56%) did not have a college degree. Forty-six (61%) were facing cancer treatment decisions and 29 (39%) were facing cancer prevention decisions. Forty-one patients (55%) reported being highly satisfied with their decisions (decision satisfaction > 5). Eleven patients (15%) chose options that were inconsistent with their physicians' recommendation. When presented with more than one treatment option, 22 patients (31%) chose the less aggressive option and 27 (38%) chose the more aggressive option.

**Table 1** Characteristics of women facing surgical decisions

	N (mean)	% (SD)
Age in years (mean, SD)	(51)	(13.3)
Level of formal education		
High school degree or less	25	35%
Some college or technical training	15	21%
College degree or more	31	44%
Numeracy—Total (mean, SD)	(4.2)	(1.3)
High ability	42	56%
Low ability	33	44%
Hispanic ethnicity	4	5%
Race		
White, not hispanic	57	76%
Other	18	24%
Disease status		
Current cancer diagnosis	46	61%
No current cancer diagnosis	29	39%
OPTION scale (mean, SD)		
Total score (original 12 items)	(2.72)	(0.73)
Uncertainty items (3 added items)	(1.33)	(0.73)

### Decision communication

Surgeons discussed general uncertainty with patients in 93% of the consultations, probabilistic uncertainty in 48% of the consultations, and evidentiary uncertainty in 28% of the consultations. The mean of the overall OPTION scale was 2.72 (SD 0.73), and the mean of the three uncertainty items was 1.33 (SD 0.73). The mean translated score of the overall OPTION scale was 68.0 (SD 18.3), and the mean translated score of the uncertainty items was 33.2 (SD 19.1).

### Hypothesis testing

Physician communication of uncertainty was not related to surgical choice, aggressiveness of surgical choice, or consistency with the multi-disciplinary team's recommendations. Patients with more years of formal education whose physicians communicated more uncertainty reported lower decision satisfaction than patients with fewer years of formal education ( $\beta = -0.40$ ,  $P < 0.02$ ). Other demographic variables and patients' numeric ability did not act as moderators of the relationship between

communication and choice, or communication and patient satisfaction. Disease status moderated the relationship between total involvement in decision making and decision satisfaction ( $\beta = -1.70$ ,  $P < 0.02$ ), and communication of uncertainty and decision satisfaction ( $\beta = -2.80$ ,  $0.001$ ). Table 2 summarizes these findings.

When we explored these relationships among cancer patients ( $N = 46$ ), physician communication of uncertainty was negatively related to decision satisfaction ( $\beta = -1.77$ ,  $P < 0.002$ ); cancer patients reported less decision satisfaction when physicians communicated more scientific uncertainty about options. Additionally, there was an interaction effect between total involvement in decision making and communication of uncertainty in relation to cancer patients' decision satisfaction ( $\beta = 2.42$ ,  $P < 0.03$ ). Cancer patients of physicians who involved them more in the decisions were less dissatisfied when presented with information about uncertainty than those whose physicians involved them less in the decision.

### Discussion

To our knowledge, this study is the first to examine the impact of physician communication of scientific uncertainty in a medical setting with patients facing actual health decisions.

Consistent with previous literature on communicating general illness uncertainty (e.g.<sup>8</sup>), physicians in our study did not frequently communicate scientific uncertainty to patients. Informed decision making suggests that physicians incorporate the best available evidence into patients' personal context and values, and assumes that uncertainty is explicitly discussed with patients.<sup>27</sup> A lack of discussion about scientific uncertainty may undermine the positive effects of shared decision making on patient outcomes such as knowledge, decision satisfaction and decisional conflict.<sup>4</sup>

However, our findings show that communication of scientific uncertainty might lead to decision *dissatisfaction* among women facing cancer treatment decisions; this finding was not found for women facing prevention decisions.



**Table 2** Summary of study findings of option scores by outcomes of interest (*N* = 75)

Option score	Outcomes					
	Decision satisfaction (highly vs. less satisfied)		Choice consistent with recommendation (yes vs. no)		Aggressiveness of treatment (more vs. less aggressive)	
	Beta	<i>P</i> -value	Beta	<i>P</i> -value	Beta	<i>P</i> -value
Overall						
Total score	0.03	0.95	0.35	0.47	−0.27	0.54
Uncertainty score	−0.51	0.15	−0.13	0.78	0.39	0.31
Moderation analyses						
Total score by uncertainty score	−0.10	0.76	−0.3854	0.36	0.41	0.28
Total score by disease status	<b>−1.70</b>	<b>0.02</b>	0.50	0.99	−0.48	0.45
Uncertainty score by disease status	<b>−2.80</b>	<b>0.001</b>	0.15	0.99	0.14	0.82
Total score by age	−0.04	0.19	0.04	0.18	−0.04	0.10
Uncertainty score by age	−0.02	0.37	0.02	0.57	0.02	0.49
Total score by education	−0.08	0.61	−0.15	0.44	0.09	0.63
Uncertainty score by education	<b>−0.40</b>	<b>0.02</b>	−0.09	0.64	−0.18	0.32
Total score by race	−1.36	0.09	0.39	0.59	0.30	0.73
Uncertainty score by race	−0.10	0.88	0.66	0.37	0.59	0.44
Total score by numeracy	−0.11	0.13	−0.06	0.33	−0.05	0.37
Uncertainty score by numeracy	−0.08	0.19	−0.13	0.12	−0.01	0.93

Bolded values are statistically significant at *P* < 0.05.

Knowledge about scientific uncertainty might add additional anxiety to individuals facing 'high stakes' decisions such as those involving cancer decisions.<sup>28</sup> Past literature has found that high levels of anxiety about illness could lead to a diminished ability to understand disease information<sup>29</sup> and to make appropriate treatment choices.

These findings amplify the debate about whether decision satisfaction is an appropriate outcome measure of a good decision-making process. Some level of decision dissatisfaction may be inherent to involving patients in decision making and ethically informing them about their choices that are often based on uncertain evidence or risks. Many argue that 'good decision quality' should be measured by patient's knowledge about options, realistic perceptions the probability of risks and benefits of options, and/or agreement between patients' preferences for options and their choices.<sup>30,31</sup> Satisfaction and decisional conflict are strongly related to the decision outcome, and may not reflect the quality of the decision process.<sup>32</sup>

Additionally, our findings suggest that physician communication may play a key role in patients' response to decision making and uncertainty. Patients of physicians who involved them in decision-making discussions reported less dissatisfaction than those whose physicians were more paternalistic in their decision communication. These findings are consistent with communication experts' plea for researchers to develop tools or training for physicians and patients to improve communication about decision making (e.g.<sup>33,34</sup>). In situations such as those involving uncertainty about cancer treatments, where communicating the unknowns are essential to treatment decision-making, physicians might lessen the impact of uncertainty on patients' distress by involving patients in decisions.

These findings should be interpreted cautiously given several study limitations. First, we were not able to audio-tape the patient-physician interactions. Although we had the same trained rater observe and code all consults to reduce the bias across ratings, we were not able to revisit consults and revise the codes. In

addition, we might have introduced some bias by having a person in the room coding the consultations, potentially leading to more communication about decisions or uncertainty. However, given the small number of clinicians communicating some types of uncertainty, this over-representation could have actually helped us to examine the impact of uncertainty communication on our outcomes. To get a more accurate understanding of decision communication, future studies should audio-record and code the consults using independent raters who have trained in the OPTION scoring system. Second, participants in our study were all women facing a decision about breast health. Some studies have found that women are more likely than men to experience decisional conflict when facing difficult health decisions.<sup>35</sup> Thus studies should examine uncertainty communication and decision satisfaction among men and/or women facing a broader range of health decisions. Third, we used a 1-item measure of decision satisfaction (e.g.<sup>16</sup>) to reduce the length of the questionnaire and participant burden. We also used a subjective scale to measure numeracy that is correlated with objective numeracy and reduces participant burden, but is not a perfect substitution for objective numeracy. Future studies could examine these findings using other measures of decision satisfaction (e.g.<sup>16</sup>) or an objective measure of numeracy (e.g.<sup>36</sup>).

To support informed decision making, patients' unique characteristics, circumstances and values need to be considered. Without an explicit discussion of the scientific uncertainty that complicates many decisions, informed decision making may fall short of its goals. As many patients face decisions that are outside the research evidence base,<sup>6</sup> it is essential that research examines the impact of communicating scientific uncertainty to patients. Communicating uncertainty should be studied in relation to overall communication and patient-physician trust<sup>9,27</sup> to explore whether physician variables such as their tolerance of uncertainty or the patient-physician relationship can lessen any potential negative impact of uncertainty com-

munication and help patients to manage the uncertainty that is inherent in many health decisions.

## Conflicts of interest

The authors do not have any conflict of interest to declare.

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